



Trustees Report for Financial year Ending June 2023

Registered Charity Number: 1184321

Address: 1354 Peartree Cir
OAKVILLE, ONTARIO
L6M 2J2
CANADA

Contact Details: Cristian Baigorria

Prepared Aug 20, 2023

Approved by Trustees: Sep 19, 2024

Table of Contents

<u>STRUCTURE, GOVERNANCE AND MANAGEMENT</u>	<u>3</u>
<u>CHARITY TRUSTEES:</u>	<u>2</u>
<u>MANAGEMENT:</u>	<u>2</u>
<u>ABOUT THE GLOBAL ALLIANCE FOR PKU (GAP)</u>	<u>2</u>
<u>GAP STRATEGY STATEMENT</u>	<u>3</u>
<u>GAP ACTIVITIES FOR 2019/2020 YEAR</u>	<u>3</u>
<u>ACHIEVEMENTS</u>	<u>4</u>
<u>FINANCIAL REVIEW</u>	<u>4</u>
<u>DECLARATIONS</u>	<u>5</u>

Structure, Governance and Management

The Global Association for PKU is a registered charity with Charity Commission of England and Wales, it is a Charitable Incorporated Organisation (CIO) governed by charitable objects.

Charity trustees:

Name	Date appointed
ALEJANDRO SPATARO	08 July 2019
LOUISE HEALY	08 July 2019 (resigned 20 APR 2023)
DENIZ ATAKAY	08 July 2019
TOBIAS HAGEDORN	08 July 2019
CRISTIAN BAIGORRIA	08 July 2019
RONALDO LOPES	08 July 2019
MONIQUE COOPER	08 July 2019
JOHN ADAMS	08 July 2019
JOSE DE JESUS MUNOZ NAVARRO	08 July 2019
LISA MILBERG	11 August 2022
RHONDA CONNOLLY	11 August 2022
BERNADETTE GILROY	13 October 2022 (resigned 27 APR 2023)

Management:

The charity has an executive committee responsible for management of the organisation. The office bearers are voted on at each AGM. GAP has a detailed constitution that describes the governance and management of the organisation including the election of office bearers, member criteria, management and trustee terms and other key governance and management issues.

Chair : John Adams

Vice-chair: Jose de Jesus Munoz Navarro

Treasurer: Tobias Hagedorn

Secretary: Cristian Baigorria

Executive Committee members: Tobias Hagedorn and John Adams

Trustees generally meet every 2 months.

About the Global Alliance for PKU (GAP)

The charity was registered in 8 July 2019. The purpose of the GAP is to: 1) To promote and protect the physical and mental health of sufferers of phenylketonuria (PKU) through the provision of support, education and practical advice and in such other ways as the trustees consider appropriate; and (2) advance the education and understanding of the general public in all areas relating to PKU. The trustees developed a strategic statement to describe how the organisation will fulfil this intent.

GAP Strategy Statement

A regional and several country-based PKU patient organizations from around the world have collaborated to form the first Global Association for PKU – known as GAP. This global entity will serve as a supportive umbrella organization to regional and national patient organizations and groups in bridging the gap for PKU worldwide.

The Organization's Vision is that all people living with PKU, despite their origin, will be able to reach their full potential.

Our mission is to advance PKU as a global health priority and strengthen PKU associations and groups throughout the world.

As people living with PKU, our priorities are:

- To create a global platform for PKU advocacy that includes ensuring universal access to newborn screening and diagnosis, treatments and comprehensive care;
- To mentor like-minded patient associations and groups and offer best practices and support that are sensitive to their experiences, culture, language(s) and laws;
- To increase collaboration among PKU researchers, scientists, clinicians and patient groups to move basic science and research forward to accelerate new knowledge, treatments, and a cure.

GAP Activities for 2022/2023Year

As a young organisation our main activities have been around establishment of appropriate governance and building the profile of the organisation in order to reach our intended targets and increase awareness of PKU worldwide.

Summary of activities:

1. Continue to develop appropriate fiscal and governance procedures to ensure compliance with charity registration requirements and to promote transparency and accountability to members and potential members, including conflict of interest policy, working with sponsors policy, financial management procedures and meeting procedures, member application procedures and fees.
2. Developed membership of the Global Association by accepting applications from the following like-minded PKU patient organisations:
 - (a) DIG PKU (German PKU Association)
 - (b) MDDA (Metabolic Dietary Disorders Association, from Australia)
 - (c) PKU Mexico (Mexican Association for PKU)
 - (d) CanPKU (Canadian PKU and Allied Disorders)
 - (e) National PKU Alliance (USA)
 - (f) PKUAI (PKU Association of Ireland)
3. Established subcommittees to function as working groups furthering the purpose and strategic intent of GAP. These include:

- I. Finance and governance
 - II. Strategic projects: a) communications, b) audit of current status of Newborn Bloodspot Screening worldwide; and c) membership development.
4. Planned and conducted an international PKU patient meeting in late 2023 – from December 13 to December 19, 2023. This virtual meeting provided awareness, education and collaboration for current and emerging PKU patient groups around the world.

The trustees of GAP continue to work to ensure that our activities result in public benefit in particular improved health outcomes for people living with PKU.

Achievements

- Establish communications and fundraising mechanisms
- Strategy for awareness and fund-raising
- Secured funding and progressed planning for the first ever global PKU patient education and awareness conference
- Established collaborative partnership with member PKU patient organisations around the world.
- Commenced strategy and tools for data collection on status of newborn screening.

Financial Review

As this is our third year of operation and due to the pandemic environment, the GAP have no reserve funds and have not spent any funds this year. The focus on the year has been establishing the appropriate legal structures, policies and procedures for the effective functioning of the charity into the future.

All trustees are volunteers with extensive experience in PKU patient organisations and have volunteered in excess of 150 hours in establishing this organisation and continue to volunteer in excess of 200 hours week in governing and managing this charity

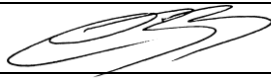
The charity is not holding any funds on behalf of others.

Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)



Full name(s)

Cristian Baigorria

**Position (eg Secretary,
Chair, etc)**

Secretary

Date

Sep 20, 2024

Charity Commission Annual Return 2023

GLOBAL ASSOCIATION FOR PKU

Charity registration number: 1184321

Most of the information you give in this form will become publicly available on the Register of Charities. Any field that the Charity Commission will not display will be clearly marked.

This document is a record of the information provided in the Annual Return 2023.

Financial period

Financial period start date

01/07/2022

Financial period end date

30/06/2023

Income and spending

Income £

£0

Spending £

£0

Number of contracts from government

How many contracts (other than grant agreements) did your charity receive from central government or a local authority during the financial period for this return?

0

Number of grants from government

How many grants did your charity receive from central government or a local authority during the financial period for this return?

0

Income breakdown

Donations and legacies (excluding Endowments Received)

£0

Charitable activities

£0

Other trading activities

£0

Investments

£0

Other

£0

Recipients of grants

Please round all figures to the nearest pound (do not enter decimal points or commas).Individuals

£0

Other charities

£0

Other organisations that are not charities

£0

Trustee payments

Excluding out of pocket expenses, for what were any of the trustees paid during the financial period for this return?

☒ e. None of the trustees have been paid

Did any of the trustees resign and take up employment with your charity in the financial period of this return?

No

Income from outside the UK

Did your charity receive income from outside of the United Kingdom in the financial period of this return?

No

Delivering activities outside the United Kingdom

Did your charity deliver charitable activities outside of the United Kingdom in the financial period of this return?

No

Spending outside England & Wales

Did your charity spend funds outside of the United Kingdom in the financial period of this return?

No

Trading subsidiaries

Does the charity have any trading subsidiaries?

No

Charity contact details correct

Is the contact address displayed from the Register of Charities, correct?

Yes

Charity headquarters details correct

Is this the same address that you use as your charity's administrative headquarters?

Yes

Charity contact address

1354 PEARTREE CIR

OAKVILLE

ONTARIO

L6M 2J2

Canada

Charity Headquarters address

1354 PEARTREE CIR

OAKVILLE

ONTARIO

L6M 2J2

Canada

Membership type

Is the charity part of a wider group structure with a parent body and subsidiary bodies?

no, the charity is not part of a wider group structure

Employment contract types

People were permanently employed by your charity

0

People were on fixed-terms contracts with your charity

0

Self-employed people were working for your charity

0

Governance policies

Internal charity financial controls policy and procedures

Yes

Safeguarding policy and procedures

No

Financial reserves policy and procedures

No

Complaints policy and procedures

No

Serious incident reporting policy and procedures

No

Internal risk management policy and procedures

No

Trustee expenses policy and procedures

Yes

Trustee conflicts of interest policy and procedures

Yes

Investing charity funds policy and procedures

No

Campaigns and political activity policy and procedures

No

Bullying and harassment policy and procedures

No

Social media policy and procedures

No

Engaging external speakers at charity events policy and procedures

No

External risk and impact**Donations,**

Unknown/No Change/Not Applicable

Other income - grants

Unknown/No Change/Not Applicable

Other income - contracts

Unknown/No Change/Not Applicable

Other income - investment

Unknown/No Change/Not Applicable

Expenditure on charitable activities

Unknown/No Change/Not Applicable

Expenditure on overheads

Unknown/No Change/Not Applicable

Number of volunteers

Unknown/No Change/Not Applicable

Number of employees

Unknown/No Change/Not Applicable

Number of trustees

Unknown/No Change/Not Applicable

Fundraising activities

Unknown/No Change/Not Applicable

Capacity to deliver services

Unknown/No Change/Not Applicable

Total service demand

Unknown/No Change/Not Applicable

Volunteers

Excluding trustees, provide an estimate of the number of volunteers who carried out charitable activities on behalf of your charity in the United Kingdom during the financial period of this return?

0

Privacy statement

Any information you give us will be held securely and processed only in accordance with the rule on data protection. We will not disclose your personal details to anyone unconnected to the Charity Commission unless:

- you have consented to their release; or
- we are legally obliged to disclose them; or
- we regard disclosure as either (a) necessary so that we can properly carry out our statutory functions or (b) necessary in the public interest.

We may share and disclose information about you with relevant public authorities, regulatory bodies and agencies, outside the Charity Commission but only if:

- we can lawfully do so; and
- we decide that disclosure is necessary for national security, crime detection, prevention, and law enforcement, or other issues in the public interest

Information we collect about you

We will use this information:

To enable us to carry out our statutory functions and duties;

This will include the following actions:

- (a) update, consolidate, and improve the accuracy of our records;
- (b) undertake crime detection and prevention and law enforcement and assist the third parties specified above to investigate or prevent crime and carry out law enforcement;
- (c) data analysis, testing, research, statistical and survey purposes

Information we receive from other sources.

Information we receive from other sources

We may combine this information with information you give to us and information we collect about you.

We may use this information and the combined information for the purposes set out above (depending on the types of information we receive).

We will ensure that any such disclosure and use is proportionate; considers your right to respect for your private life; and is done fairly and lawfully in accordance with the data protection principles of the Data Protection Act.

The Data Protection Act 1998 regulates the use of 'personal data', which is essentially any information, however stored, about identifiable living individuals.

As a 'data controller' under the Act, the Charity Commission must comply with it. Any changes we may make to our privacy statement in the future will be set out in the replacement version of this form.

Please check back frequently to see any updates or changes to our privacy policy.

Declaration

Your role at the charity (select one):

☒ Trustee

Given names

CRISTIAN

Family name

BAIGORRIA

Telephone number	+1 6472442592
Email	cristian.baigorria@globalpku.org
Date submitted	20/06/2024

It is a criminal offence under section 60 of the Charities Act 2011 for anyone to knowingly or recklessly provide false or misleading information to the commission; this includes suppressing, concealing or destroying documents.